Developmental Disabilities

Residential Study Advisory Council Meeting Notes

November 18, 2005 (9:00 am-3:15 pm)
Seattle Sea-Tac Hilton

Council Members Attending: Dale Colin, Greg Devereux, Lori Flood, Marcy Johnsen, Kathy Leitch, John Mahaney, Lance Morehouse, Karen Ritter, Senator Dale Brandland, Senator Adam Kline, Representative Brendan Williams, Representative Jan Shabro, Kari Burrell

Guest Legislator: Representative Maralyn Chase

Staff Members Attending: Sharon Swanson, Chelsea Buchanan, Amy Hanson, Sydney Forrester, Donna Patrick, Tom Lineham, Don Clintsman, Gaye Jensen, and Facilitator Marge Mohoric

Guest Staff Attending: anita delight, Ron Sherman, and Tom Kearns

Meeting Purpose:

1. To continue clarifying the work of the Council and defining the key issues that the Council is addressing
2. To gain a basic understanding of Medicaid, DD eligibility and assessments, and costs of residential services
3. To begin thinking about the January 1, 2006 Report
4. To identify topics for discussion at the December meeting

Facilitator Marge Mohoric reviewed the agenda and asked Council members "given the agenda and all that we will be covering, what is one thing you would like to see accomplished today?" Following are their answers, and their assessment at the end of the day about whether their goals were accomplished.

Member	Goals for the Day	Accomplished?	
		Yes	No
Dale Colin	Agree on what we have to do and when we will finish—end of Jan seems impossible		X
Greg Devereux	Get closer to our purpose and to some of the main issues for future meetings	X	
Lori Flood	Have an action plan of what we will do in reference to what Senator Brandland brought up last meeting—need to be sure accurate information is presented		X

Member	Goals for the Day	Accomplished?	
		Yes	No
Marcy Johnsen	To be able to see where our differences are and what do we need to do to reconcile them	Partly	
Kathy Leitch	Finish the overview parts and begin the discussion of the issues and get into the hard work	Partly	
John Mahaney	Accomplish the agenda	X	
Lance Morehouse	Get to the project framework part of the agenda and get process questions answered (NOTE: Lance had to leave before the meeting adjourned)		
Karen Ritter	Get through information section and begin creating plans—new ideas		X
Senator Dale Brandland	Identify new information piece, if any (NOTE: Senator Brandland needed to leave at 2pm)		
Senator Adam Kline	Come to a point where the RHC and community groups put together proposals that will reflect their feelings of where they think we should go—and then have give/take on all sides		X
Representative Jan Shabro	Description of services—comparing costs—to feel comfortable that I have sufficient information and that we are comparing apples to apples		X
Representative Brendan Williams	Our agenda has reasonable objectives—in the longer term what Sen. Kline said is totally reasonable	X	
Kari Burrell	Want to do this project in phases; we're in data gathering now and make sure they answer all the questions and then move forward	X	

Gaye Jensen—Follow-up Announcements

- The Governor's website has a link to the DD Residential Study Advisory Council's purpose and progress http://www.governor.wa.gov/disabilities/default.htm
- Staff has available data that were requested by several Council members

Amy Hanson—Medicaid Basics

- Refer to PowerPoint presentation
- Questions/Clarifications
    1. Clarification of process for waiving rights to ICF-MR placement

Don Clintsman and anita delight—Assessing Eligibility for Residential Services

- Refer to PowerPoint presentation
- Questions/Clarifications
    1. Data on clients who are eligible for medically intensive program
    2. Description of levels for community residential services
    3. Data on individuals admitted to RHCs—mostly long-term respite?
    4. Is there data on statistics for children in out-of-home placements where there is collaboration with DCFS?

Gaye Jensen—Project Framework: beginning the discussion of what a "preferred system" would look like (Council created brainstorm list of answers to three questions):

- **Who are the people who rely on the publicly funded system of residential services for people with developmental disabilities?**
    1. Adults with DD
    2. Staff (state and private)
    3. Families
    4. Citizens and community

- **What do they rely on this system of residential services for?**
    1. Home care
    2. Roof over their heads
    3. Safety and health
    4. Personal choices
    5. People rely on residential programs for choices
    6. Supervision
    7. Adaptive equipment
    8. Independence
    9. Learning
    10. Integration
    11. Community access
    12. Continuing (in the community model) of the home environment they may have experienced with their families
    13. Stability
    14. Continuity
    15. Valuing staff
    16. Sometimes staff are their family
    17. Employment

18. Communication—particularly for people who are not verbal, staff can communicate their needs
19. Recognizing when a person isn't well—relying on staff
20. Helps families plan for the future
21. The kind of choices that living in the community offers

- **An effective public system of residential services would:**
    1. Be flexible to meet people's needs in the most integrative setting
    2. Include options/choices
    3. Provide a continuum of care
    4. Provide stability in care from birth to death
    5. Be something available to that individual in their home community where they have developed natural supports
    6. Provide a living wage and consistency for the providers themselves
    7. Have a system of checks and balances so people wouldn't fall through the cracks
    8. Provide quality assurance
    9. Be balanced with protections but not too much red tape
    10. Include adequate funding

Tom Lineham, Chelsea Buchanan, Tom Kearns, Ron Sherman—Current Residential Services for People with Developmental Disabilities: Descriptions, Clients and Costs

- Refer to PowerPoint presentation
- Questions/clarifications
    1. How does the IMR tax work?
    2. Past census of RHCs?
    3. Utilization data for YVS respite care (planned respite vs. crisis)
    4. How do states w/o institutions provide respite care?
    5. Comparison of RHC nursing home acuity data to community nursing homes
    6. Any data on staff ratios for community residential programs?
    7. Medical costs for clients in nursing homes that are paid outside of the rate
    8. Liability and cost data?

Kari Burrell—January 1, 2006 Draft Report to the Legislature

INTERIM REPORT OUTLINE (for Council members to consider)
INTRODUCTION
METHODOLOGY
DESCRIPTION OF CURRENT STATE-FUNDED RESIDENTIAL PROGRAMS
ADDITIONAL DATA NEEDS
PROPOSED 2006 ADVISORY COUNCIL ACTIVITIES
INTERIM REPORT RECOMMENDATIONS

- Extend the work of the Developmental Disabilities Residential Study beyond December 31, 2005

- Revise the date of the Final Report to the Governor to_____

December 15, 2005 Council Meeting—Proposed Agenda

1. Discussion of available cross-state comparison data
2. Emerging issues that relate to residential services
3. Additional data needs?
4. Acuity: low/medium/high
5. Respite care issue
6. Discuss interim recommendations to be included in the January report to the legislature
7. Emerging Issues (staff may provide issue papers with data and some discussion points)
   - Demographic trends that may drive increased rate of demand?
     - Aging caregiver issues
   - What is the capacity of the system?
   - Pressures on the community residential system
     - Pressures on the community as a result of community residential settings
   - Capital infrastructure needs at the RHC's
   - Prioritization criteria if new funding is available
   - Waitlists
   - Impacts associated with restructuring
     (Council member suggested holding this agenda item until future meetings)

Public Comments--What feedback do you have on today's presentations? Was there anything missing?

Commenter 1:
It is important not to assume that "of the 10,500 waiver slots" not all 10,500 have been revisited to ask the question "are you interested in RHC services?" It was not the mind set of DDD to open admissions. Are we sure they have asked?

Commenter 2:
Missing: medical doctor with experience working with DD medical fragile patients; VIP on committee. Missing: ICF/MR representatives on Committee, VIP

Commenter 3:
Any service currently provided by the RHC's is available in the community, including 24-hour respite care. The same hour of support does NOT cost the same regardless of setting. What exactly is the difference in the nursing home care provided by the state vs.

nursing home care provided by the community? Don't they both have the same certification requirements? Visit community programs, please.

Commenter 4:
Very concerned that National trends on closure and downsizing of institutions was not shared. This is a post institutional time in most states—why are we stuck on this again. People are not widgets. Quality of life has not been addressed—there are many studies that show people's lives have improved when they return to community—why rates but not quality of lives?

Commenter 5:
Olmstead "requires" that people be served in the "least restrictive setting." Look at law suits across the country to enforce Olmstead and community options. Get copies of the Braddock "State of the States" data—information on states that have closed all of their state institutions. Closure can happen if the Legislature allocates adequate funding for needed community services and living wages for care providers. Fodor homes mentioned by Representative Chase are not funded by DD.

Commenter 6:
Assessment tools: anita delight—suggestion, before assessment tools are finalized, the people who devise them should personally follow through in entirety in their use. The assessment tools leave much to be desired and need both major revisions and fine tuning to be accurate.

Commenter 7:
Missing is a council member who currently lives in an RHC as required by the Legislation which created the Council. The legal voices of RHC residents and their count appointed guardians. Why should RHC's be in DSHS at all? The other Article 13 (State Constitution) institutions: prisons and universities/colleges are not under other departments. DSHS is historically hostile to RHC's. Let's examine relocation trauma.

Commenter 8:
Let's stop saying who is on first and focus on the client's needs.

Commenter 9:
What happens to an individual's SSI in the RHC? How are outside medical issues paid for at the RHC's? What is the respite analysis—acuity at RHC's vs. community?

Commenter 10:
The financial presentations admitted large gaps in data which prevent apples to apples comparisons. This is why we need a well done, thorough study that accumulates all of the data. Until that is done, trying to determine if some venue is more cost effective in general is not a productive endeavor. Let's do it right this time.

Commenter 11:

Today and at the last meeting “trends” toward smaller living situations have been referenced. It is true, but not acknowledged that the “trends” are policy driven, especially because of DSHS’s preference for community placement. Case managers tell us that their jobs would be in jeopardy if they were to offer RHC placement. This means that the “trend” toward RHC downsizing/closure is done to DSHS intent and is not a natural trend. In the future, please replace the word “institution” and “institutional” to “RHC” or “nursing home” or “community ICFMR” placement. They are all institutions.

Commenter 12:
We would like to have this Council address the degree of oversight required/provided for each residential program venue. We would like to have this Council consider and recommend a system of community venue oversight which prevents the problem of the fox watching the henhouse that exists as DSHS is the agency which provides the oversight. In RHC’s oversight is done by DSHS on behalf of AMS by their standards—with strong incentive for passing audits and compliance with standards. Ideally this Council can suggest something similar, even without the Federal component. This is in the interest of client safety and quality of life.

Commenter 13:
Tom Lineham’s presentation included JLARC land use recommendations from 2002 study: (a) that study assumed an RHC should be closed. It started there. (b) An alternative recommendation for the use of Fircrest property was to site government offices on the unused portions of the property while continuing to operate the RHC there. The JLARC Land Study was not concerned with client needs or services and, therefore, should not provide basis for decisions.

Commenter 14:
Full range of cost of care in the community room board, care, medical, dental, education, job training (see 11/18 testimony from FOF/Action for RHC’s). We are talking about RHC costs so we need to talk about full community costs, including hospital admits and ER visits. We need a study that includes all costs.

Commenter 15:
Why do you use the terminology “at risk for institutional placement” it appears to me that community ICF/MR are also institutions. CMS definition of a institution is 4 clients. This encompasses most “community” placements. If you are speaking of the RHC’s, what is the risk, the RHC’s provide comprehensive care in the least restrictive setting (Olmstead).

Commenter 16:
If this council's mandate is taken seriously, it will lay the groundwork for a system of services delivery which will affect the lives of people with developmental disabilities for many years to come. In addition to providing basis for appreciation of the current DDD delivery system, the presentations of the last two meetings provided, to some extent, a window into what facts (data) are not known or even kept. Far too frequently, the answers to questions about how much services cost have been met with answers such

as, " we do not have that data because those services are provided by other agencies" or , "that data is hard to get because of how the system is designed." The problem of not having complete and accurate data, very precisely, is responsible for a large part of the misunderstanding between people who support Community care only and those who require that RHCs be a necessary part of the continuum of care. If the two sides ever are to come together for the good of those who need the services, all of the data must be available to make APPLES to APPLES comparisons. Only when all of the cost data is known, and all of the needs and available services data is known will there be credible basis for comparisons, and only then will it make sense to address how to use the resources to provide the needed services.

It is not enough to understand that the data is "hard to get." To fullfill their mandate, members must insist that, where absent, collection systems be designed and implemented to acquire the data to make APPLES to APPLES comparisons. It is a shame that the data is not already available, but it would be a travesty and irresponsible to make such important decisions without it, even if acquiring it takes longer than planned.

Facilitator Marge Mohoric asked the Council to debrief today's meeting:

Today's Meeting—What Went Well?

- Liked the way the meeting went; more respect in room; liked lunch arrangement
- Appreciate Marge keeping us on track and making sure public comments are not forgotten
- A lot of hard work was done by the presenters

Today's Meeting—What Could Have Been Improved?

- Reliable information
- Compare apples to apples
- Have more parking available

The meeting adjourned at 3:15pm.

Note:

At the conclusion of the meeting, some members of the audience provided written handouts for Council members. These documents are not part of the electronic record. However, to request a copy, contact Gaye Jensen at (360) 902-0551 or e-mail gaye.jensen@gov.wa.gov.